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DOI:

[10.1186/s13104-015-1102-3](https://doi.org/10.1186/s13104-015-1102-3)

Document Version

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Singh, T., & Harding, R. (2015). Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes. *BMC Research Notes*, 8, [172]. <https://doi.org/10.1186/s13104-015-1102-3>

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RESEARCH ARTICLE

Open Access

Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes

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Abstract

Background: The increasing incidence of cancer and chronic diseases in South Asia has created a growing public health and clinical need for palliative care in the region. As an emerging discipline with increasing coverage, palliative care must be guided by evidence.

In order to appraise the state of the science and inform policy and best practice in South Asia this study aimed to systematically review the evidence for palliative care models, interventions, and outcomes.

Results: The search identified only 16 articles, reporting a small range of services. The 16 articles identified India as having greatest number of papers ($n = 14$) within South Asia, largely focused in the state of Kerala. Nepal and Pakistan reported a single study each, with nothing from Bhutan, Afghanistan, Maldives or Bangladesh. Despite the large population of South Asia, we found only 4 studies reporting intervention outcomes, with the remaining reporting service descriptions ($n = 12$).

Conclusions: The dearth of evidence in terms of palliative care outcomes, and the lack of data from beyond India, highlight the urgent need for greater research investment and activity to guide the development of feasible, acceptable, appropriate and effective palliative care services. There is some evidence that suggests implementation of successful and well-developed community based models of palliative care may be replicated in other resource limited settings. Greater investigation to determine outcomes and costs are urgently needed, and require well-designed and validated tools to measure outcomes. Studies are also needed to better understand the cultural context of death and dying for patients and their families in South Asia, and to respond to the growing need for palliative and end-of-life care in the region.

Keywords: Palliative care, Systematic review, End-of-life, Terminal, Asia, South Asia, Palliative care models

Background

The World Bank defines the subcontinent of South Asia as Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka (also known as the South Asian Association of Regional Cooperation Countries, or SAARC). It has a combined population of about 1.65 billion, or almost a quarter of the total of the world's population, and all SAARC countries are classified as lower middle or low-income countries [1]. An estimated 571 million people in South Asia survive on less than USD 1.25 a day, and they comprise more than 44% of

the developing world's poor (GNI per capita 1,483 USD, 2013) [1].

The International Agency for Research on Cancer (ICAR) estimated the number of new cancer cases annually in South Asia to be around 1.33 million cases (1 million in India, 148,000 in Pakistan, 122,700 in Bangladesh; Nepal 18,800, Sri Lanka 23,700, Afghanistan 20,000, Bhutan 500 and Maldives 200) [2]. In India, more than 80% of cancer patients present at stages 3 and 4 [3]. In addition to late presentation, other factors that increase the need for palliative care include inadequate diagnostic facilities and assessment skills; poor availability of chemotherapy and radiotherapy; and absence of opioids [4]. GLOBOCAN, estimated that there were 919,400 cancer deaths in the year 2012 in South Asia [2,5]. The most

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recent UNAIDS country data (2012) estimates between 2 and 2.5 million people living with HIV and AIDS in South Asia, and 150,000 HIV-related deaths [6]. Incidence of other chronic diseases, including end-stage heart failure, renal and respiratory diseases, are projected to rise [7-9]. The field of palliative care global health is gaining greater attention, aiming to establish appropriate, locally relevant, feasible and effective palliative care for all irrespective of diagnosis, place of care or geographical region [10]. The most recent global classification of palliative care provision found no evidence of palliative care provision in 19 Indian states and union territories [11]. India and Nepal are categorized under Group 3b, defined as having 'generalised palliative care provision'. Pakistan, Bangladesh and Sri Lanka are categorized to Group 3a, with 'isolated palliative care provision'. Afghanistan, Bhutan and Maldives are categorized as Group 1, as there is no known hospice or palliative care activity [12].

The implementation of the WHO's public health approach to palliative care focuses on education, drug availability, policy and implementation [13], but in addition requires local evidence to underpin strategic development of this strategy [14]. Other low income regions (principally sub-Saharan Africa) have used systematic reviewing of the state of palliative care evidence in order to identify and appraise the existing evidence base [15,16], to highlight the required direction in order to achieve quality coverage for all [17], and subsequently to rapidly grow the evidence base [15,18-22]. In order to catalyse evidence-based policy, funding and practice, and to identify evidence gaps, the aim of this systematic review was to identify and appraise the existing evidence for palliative care models, interventions and outcomes in South Asia.

Methods

The study implemented a systematic literature review in line with PRISMA guidance [23].

Search strategy

The following databases were searched in July 2013: Ovid MEDLINE® (1980–2013), PsycINFO (1980–2013), EMBASE (1980–2013) are presented in Table 1 search strategy. The search was updated in Feb 2014, and hand searches were conducted of the *Journal of South Asian Development* and *Indian Journal of Palliative Care*. Reference lists from retrieved articles were subsequently hand searched.

See search terms and inclusion exclusion criteria subsection below:

Search terms:

The union of the following keywords:

- (hospice, terminal, terminal care, terminally ill, palliat*, hospice*, dying, end of life, advanced

disease, life-limiting, life-threatening, death, bereavement,)

intersected with the union of the following keywords

- (Asia, South Asia, SAARC, India, Pakistan, Bangladesh, Afghanistan, Nepal, Sri Lanka, Bhutan, Nepal and Maldives)

Inclusion/exclusion criteria

Inclusion

Data on care for human subjects

Reported in English language

Peer reviewed journal publication

Data from at least one of the SAARC countries

Data reporting palliative care models (delivery, organisation or content), interventions or outcomes using any study design from at least one of the following settings: home or community care; terminal care; inpatient care; daycare; hospital/acute settings; hospice care; primary care; nursing home; professional or volunteer/lay services; private or government tertiary services; cancer centers; governmental or non-governmental provision; daycare; domiciliary services;

Exclusion

Case studies, commentaries, editorials and case reviews

Grey literature

Heterogeneous samples that did not disaggregate patients under palliative care.

Data extraction and analysis

The search was conducted by TS, and the appraisal of articles against inclusion/exclusion criteria agreed with RH. Data were extracted from the retained papers and entered into common tables. The common data extraction headings were country, aims, methods, sample, service description (with subheadings of structure, provision, activity and funding, each populated according to available information), findings, lessons and comments. This enabled aims, models, study designs and findings to be potentially compared. Once the search was conducted, a post-hoc decision was made not to apply quality criteria or to conduct meta-analysis due to the heterogeneity of aims and designs, and low volume of outcome data.

Results

The papers yielded by the search strategy are reported using the PRISMA flow chart in Figure 1. A total of 16 studies were retrieved and met the inclusion criteria.

The data extraction findings are reported in Table 2.

Summary of aims and countries of origin

Of the 16 articles retained, 12 reported service description [24-35], 2 reported service with evaluation data [36,37]

Table 1 Search strategy

#	Searches	Results
1	hospice.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	27026
2	terminal.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	791480
3	terminal care.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	44526
4	terminally ill.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	22478
5	palliat*.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	163014
6	hospice*.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	29311
7	dying.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	82104
8	end of life.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	31866
9	advanced disease.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	30523
10	life-limiting.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	1977
11	life-threatening.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	122999
12	death.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	1327164
13	bereavement.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	19321
14	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13	2372812
15	Asia.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	148258
16	South-Asia.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	4821
17	SAARC.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	39
18	India.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	228512
19	Pakistan.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	33005
20	Bangladesh.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	20922
21	Afghanistan.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	9927
22	Nepal.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	13672
23	Sri Lanka.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	11947
24	Bhutan.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	733
25	Maldives.mp. [mp = ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, an, ui, tc, id, tm]	376
26	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25	415069
27	14 and 26	20649
28	limit 27 to english language	18910
29	limit 28 to human	17046
30	limit 29 to yr = "1980 -Current"	16470

Database(s): **Embase** 1980 to 2013 Week 33, **Ovid MEDLINE(R)** 1980 to August Week 3 2013, **PsycINFO**, 1806 to September week 1 2013.

and 2 reported outcomes [38,39]. 1 article aimed to collect evaluation data, but actually presented only descriptive data [32]. 14 articles reported data from India, 1 from Nepal [34] and 1 Pakistan [30]. No articles were found originating from Afghanistan, Sri Lanka, Bhutan, Maldives, or Bangladesh. Of these 16 papers, the first was published in 1997, and 6 were published during 5 years prior to the search.

Service descriptions

The 11 service descriptions addressed a diversity of care models including home care, cancer centres, hospital consult teams and outpatient clinics. The teams were largely multi-professional, and addressed holistic care needs with an emphasis on rehabilitation and socioeconomic support. The Kerala model is well described in the literature, with a

strong community participation approach. Importantly, two pediatric palliative care services were described [30,34].

Methodological designs & findings

The four papers reporting service evaluations or outcomes used the following designs: a retrospective survey [36] a retrospective file review [37] a prospective longitudinal cohort [38], and a prospective cohort with control comparison group [39] and (as stated above, one paper described as an evaluation only provided service description data). No (quasi) experimental designs were identified.

In terms of the findings, significant improvements in self-report pain among cancer patients were reported (although this prospective study lacked a comparison group [38] and improvements in satisfaction and pain relief reported

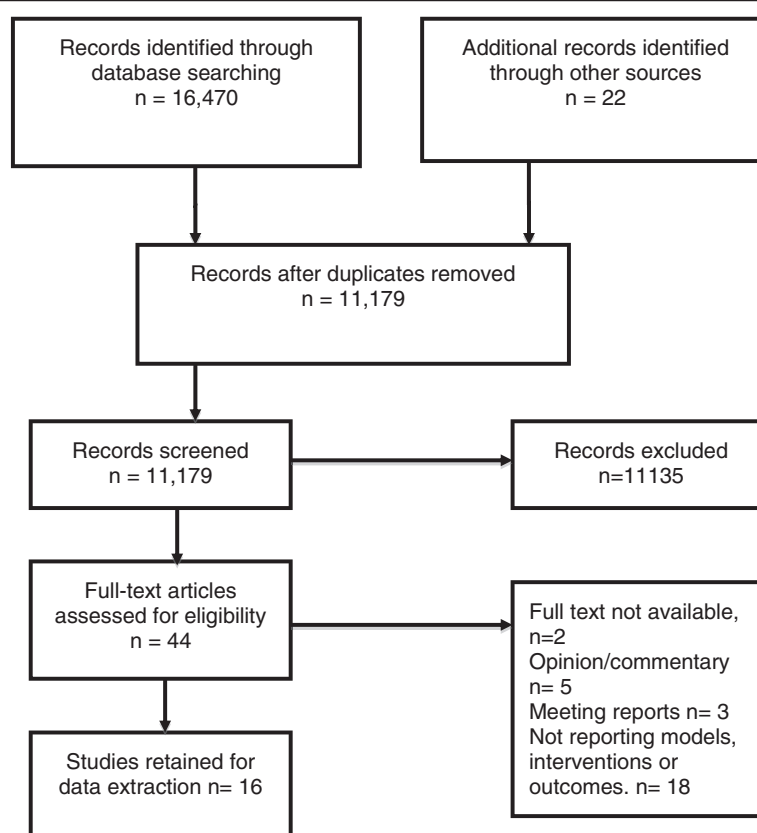


Figure 1 PRISMA flow chart of search strategy.

(although this was retrospective, and again had no comparison group [36]. The prospective comparative cohort study of palliative care for older people found perceived physical quality of life and psychological support among elderly persons was significantly better than the control villages [39], and lastly the retrospective file review of patient problems found a high prevalence of multidimensional needs but did not offer change data to support the conclusion that the service controlled these problems [37].

Discussion

It is notable that despite the large population and epidemiology of cancer and HIV, there is very small evidence base from which to determine optimal models and interventions of care. It is a strength that there is such innovation and diversity of models, and the Kerala model has been well described and lauded as an appropriate model which other regions may usefully replicate. In terms of the evidence of feasibility and acceptability of palliative care, India has the strongest available literature from the South Asia region. Indian services should be recognised for their commitment to development and implementation of care services, and neighbouring SAARC countries should be encouraged and enabled to improve their coverage similarly. The work to date on model development and initial evaluation places

India in particular in a position of readiness to move to more robust outcomes-focused research. The data provides some data on identification of needs, change over time within cohorts under palliative care, and importantly has been generated across diverse settings. In order to move to robust (quasi) experimental evaluative study designs appropriate for palliative care populations, [40] an important next step is the provision of appropriate, valid and reliable outcome measures that reflect the needs of patients and families in India facing life-limiting progressive illness. The development of validation of outcome measurement for African palliative has catalysed research activity in palliative care [41,42]. Palliative care research in India is timely, as palliative care services have been shown to be plausible and sustained. The apparently successful Indian public health approach to palliative care in Kerala should be evaluated to identify and share successful strategies and lessons learned. Additional lessons that are worthy of investigation are the strengths, challenges and mechanisms of volunteerism in India, and the financing models of services that are community-funded and supported. In light of the service descriptions of paediatric palliative care, it has previously been identified that little evidence exists on outcomes of such models in low and middle income countries [16], and we would urge a research focus on this specific population.

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia

Author& Year, Country, Facility, Reference	Service/intervention	Aim, methods, sample	Findings	Conclusions
Care models (descriptive)				
Ajithakumari <i>et al.</i> , 1997 <i>India</i> . The Pain and Palliative Care Society of Calicut [24]	<p><i>Structure:</i></p> <p>One doctor with active participation of trained community volunteers.</p> <p><i>Provision:</i></p> <p>Free community-based outpatient clinics, home care service.</p> <p><i>Activity:</i></p> <p>3 to 4 visits per day for 2 days a week.</p>	Descriptive only (first year of operation).	N/A	N/A
Seamark <i>et al.</i> , 2000, <i>India</i> . Models of care across India [25]	<p><i>Inpatient care units:</i></p> <p>a) Hospices</p> <p>Shanti Avedana Ashram, branches Mumbai, Delhi and Goa.</p> <p>b) Government Regional Cancer Centres:</p> <p>11 Government Regional Centres. Few focus on symptom relief:</p> <p>-Regional Cancer Centre, Trivandrum, Kerala.</p> <p>-Palliative Care Centre, Calicut, Kerala.</p> <p>-Pain clinic at Kidwai Memorial Institute of Oncology, Bangalore.</p> <p><i>Domiciliary Services:</i></p> <p>-Found in Bangalore, Calicut and Delhi cities.</p> <p><i>Combined Inpatient and training centre;</i></p> <p>-Cipla Cancer and Palliative Care Training Centre, Pune, funded by pharmaceutical company.</p> <p><i>Palliative Care education centre;</i></p> <p>-Calicut Center</p> <p>-Shanti Avedna Ashram, Mumbai.</p>	Descriptive only	N/A	N/A
Rajagopal and Palat, 2002, <i>India</i> . Models of Palliative Care in Kerala A) Pain and Palliative Care Society (PPCS)- B) Palliative Care Patient's Benefit Trust (PCPBT)C) Wayanad Palliative Care Consortium (WPCC) [26]	<p>A) PPCS</p> <p><i>Provision</i></p> <p>Outpatient clinic, home visits and inpatient care, educational programs (certificate and diploma programs).</p>	Descriptive:	N/A	N/A

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

Bollini <i>et al.</i> , 2004 <i>India</i> . Pain and Palliative Care Society (PCCS) [27]	Activity:				
	27 districts of Kerala via out reach link clinics.				
	B) PCPBT				
	Provision				
	Rehabilitation of patients and families, their children education support. Also provide financial support for those who lost livelihood due to disease.				
	C) WPCC				
	Structure				
	Regional cooperation model between Govt. hospital, Church and Hindu religious organization.				
Bollini <i>et al.</i> , 2004 <i>India</i> . Pain and Palliative Care Society (PCCS) [27]	Structure	Descriptive only	N/A		N/A
	Free of charge community-based services				
	Provision				
	Outpatient clinics, supportive home care services, rehabilitation, health professionals' training, active participation of trained community volunteers.				
	Most centres licensed to keep oral morphine.				
	Activity				
	In 2002, 33 clinics seeing 2000 new patients				
	Funding:				
	Private donations and international donors.				
Paleri & Numpeli, 2005, <i>India</i> . Models of palliative care in North Kerala [28]	Structure:	Descriptive only	N/A		N/A
	Volunteers raise funds; provide social, spiritual and financial support to patients; organise rehabilitation programme.				
	Provision:				
	100 palliative care services in the India with 65 centres in Kerala. 57 belong to Neighbourhood Network in Palliative Care (NNPC).				
	20 palliative care units				
	40 home care programme				
	Activity:				

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

Kumar, 2007, <i>India</i> . Neighborhood Network in Palliative Care" (NNPC) [29]	350 home visits /week Trained 3000 volunteers. <i>Finance:</i> 90% funds raised by local community through donations. <i>Referral criteria:</i> Cancer, HIV/AIDS, paraplegia, stroke, old age and debility, psychiatric illness and chronic airway disease.				
	<i>Structure:</i> Network to empower local community volunteers to identify and provide long term care and palliative care. More than 60 units covering population around 12 million <i>Provision:</i> Regular psychosocial and spiritual support. Home care with outpatient clinical and inpatient units in support. Identifying financial problems, patients in need of care. Create awareness in the community. <i>Activity:</i> 4000 volunteers, 36 doctors and 60 nurses taking care of approx. caseload of 5000 patients. Volunteer training –16 hours theory session + 4 days clinical training under supervision. <i>Funding</i> 90% funds raised locally.	Descriptive only: services/ component offered.	N/A		N/A
Brown <i>et al.</i> , 2007, <i>Nepal</i> Collaboration of Nepalese International Network for Cancer Treatment and Research (INCTR) and Nepal Palliative Care Group. Collaboration [30]	<i>Structure:</i> Hospice Nepal: 10 bedded, provides home care services, professional education Kanti Children's Hospital: sole paediatric palliative care service in Nepal. 2 beds for terminally ill. Scheer Memorial Hospital: outreach programme to care patients in rural regions, conduct education programme. Bhaktapur Cancer Hospital: 5 inpatient palliative care beds for, outpatient clinics 2	Descriptive	N/A		N/A

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

	days/week. 24-hour phone helpline, counseling service.			
	B.P Koirala Memorial Cancer Hospital: Hospice service, home-based care to terminally ill patients including HIV.			
	<i>Joint activity:</i> Education and training for professionals, development of clinical guidelines.			
McDermott <i>et al.</i> , 2008, <i>India</i> . Palliative home care services in India [31]	<i>Kerala:</i> PPCS, NNPC	Aims:	138 organizations providing hospice and palliative care services in 16 states and union territories. Concentrated in large cities with the exception of Kerala (n = 63).	Barriers to development include: poverty, population density, geography, opioid availability, workforce development, and limited national policy.
	<i>New Delhi:</i> CANSupport	1-Systematic overview of current palliative care services across the India	No provision in 19 states/union territories.	Western concept of hospice and palliative care is reshaped to suit the diverse local economic, social and cultural needs.
	<i>Assam:</i> Guwahati Pain and Palliative Care Society (GPPCS):	2-Identify strengths and weaknesses in palliative care development	Nongovernmental organizations, public and private hospitals, hospices are main providers.	
	<i>Structure:</i> Volunteer-based	<i>Methods:</i> -synthesis of peer review and grey literature		
	<i>Provision:</i> Outpatient clinic, home-care service	-ethnographic field visits -qualitative interviews n = 87 palliative care experts from 12 states		
	<i>Coverage:</i> 3 towns in Assam (Rangia, Digboi, and Hojai)	-collation of existing public health data		
Banerjee, 2009, <i>India</i> . CANSupport Home based palliative care for terminal cancer patients [32]	<i>Structure:</i> 10 home care teams, each with doctor, nurse and counsellor.	Evaluation of effectiveness of homecare teams visit in terminal cancer patients (palliative care). Only presents service descriptive data. .	N/A	

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

	Community network officials, administrative staff				
	<i>Provision</i>				
	Home visiting, psychological support, bereavement visit, medicines aid.				
	Telephone helpline active for 8 hours/day for 5 days a week.				
	<i>Activity:</i>				
	Total patients seen by homecare teams in 2008–2009 were 1025. 104 patients were discharged. Each team travels 50–150 km per day. 4–7 home visits/day by team. First visit–approx. 90–120 minutes. Subsequent visits 30–45 minutes. Usual 1–2 months under care.				
Sallnow <i>et al.</i> , 2009, <i>India</i> . Neighbourhood Network in Palliative Care (NNPC) [33]	<i>Structure:</i> Home-based model of palliative care in 14 districts of Kerala, 230 clinics, 60-full time doctors and 150 staff nurses, 200 auxiliary nurses and 10,000 trained volunteers	Descriptive: components of NNPC	N/A		N/A
	<i>Provision</i>				
	Home care, outpatient clinics and in-patient services at Institute of Palliative Medicine (IPM) and private hospital free of charge. Medical and nursing care, spiritual and psychological care, medications, training of family members.				
	<i>Activity</i>				
	2500 patients/week				
	<i>Referral:</i>				
	End stage, non-malignant conditions (50%)Cancer patients (30%), HIV/AIDS, chronic psychiatric and problems related to old age				
	<i>Funding</i>				
	Raised by local community, small donations from community, government of Kerala and some international agencies.				
Shad <i>et al.</i> , 2011, <i>Pakistan</i> . A) Shaukat Khanum Memorial Cancer Hospital and Research Center B) Aga Khan University	A) <i>Structure:</i> Palliative-care physician and nurses.	Descriptive only	N/A		N/A

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

Hospital in Karachi C) Paediatric palliative care [34]	<p><i>Provision:</i></p> <p>Inpatient care, outpatient clinics, 24-hour telephone helpline, pain management, training for physicians.</p> <p>B) <i>Structure:</i></p> <p>Palliative care physician, nurse and social worker</p> <p><i>Provision:</i></p> <p>Inpatient, outpatient service and home care as well, training seminars</p> <p>C) Children Cancer Hospital, Karachi and Children Hospital, Lahore,</p> <p><i>Structure:</i> small inpatient units.</p>	Descriptive	N/A	Awareness achieved through civil society organizations, media and by NRHM. Decentralized system of governance in Kerala enabled palliative care provision.
Kumar, 2013, <i>India</i> Kerala State model of palliative care [35]	<p><i>Structure:</i> 90% of all palliative care programs are in state of Kerala, which constitutes 3% of the total population of India. Incorporation of palliative care in the primary healthcare system and public health model initiated by National Rural Health Mission (NRHM) with the palliative care policy of government of Kerala</p> <p><i>Provision:</i></p> <p>Medical and nursing services like outpatient clinics home care service by volunteers, nurses and doctors Regular supply of food for needy families.</p> <p>Support for children from families of poor patients to continue their education.</p> <p>Transport facilities to referral hospitals.</p> <p>Rehabilitation. Psychological support by trained volunteers. Awareness campaign through local media.</p> <p><i>Funding:</i></p> <p>State funding by ministry of health, NRHM, and local self-government.</p>	Descriptive	N/A	Awareness achieved through civil society organizations, media and by NRHM. Decentralized system of governance in Kerala enabled palliative care provision.
Outcomes (evaluation data)				
Bisht <i>et al.</i> , 2010, <i>India</i> . Evaluation of QOL and pain as an outcome variable of palliative care in advanced cancer patients [38]	<p><i>Structure:</i></p> <p>Oncology clinics of a tertiary teaching hospital.</p>	<p><i>Aim:</i></p> <p>To evaluate the outcome of palliative care in terms of</p>	<p>T0 N = 100</p> <p>T1 N = 93</p>	Within palliative care, pain management is key in improving quality of life of advanced cancer patients.

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

		quality of life and pain control.	
	<i>Provision:</i>	<i>Study design:</i> Observational prospective Study with 2 month follow-up.	T2 N = 51
	Pain management, palliative chemotherapy, surgery and radiotherapy.	N = 100, mean age 52.57 years.	T0 62% reported pain
	Home care.	<i>Measures:</i> Visual 10 point analogue scale (unspecified).	T1 3% T2 1%
		The City of Hope Medical Centre Quality of Life survey.	Reduction in pain VAS scores (mean \pm SD) in from T0 to T1 [7.13 \pm 2.2 vs. 2.62 \pm 2.1 ($p < 0.001$)]. Improvement in the QOL scores [919.78 \pm 271.3 vs. 1280.65 \pm 306.8 ($p < 0.01$)]. At T2 1405.49 \pm 368.3 ($p < 0.01$) Moderate correlation between pain intensity and quality of life scores ($r = 0.53$, $p < 0.001$).
Santha, 2011 <i>India</i> . Pain and Palliative care units (PPC), Ernakulum district, Kerala, home care services [36].	<i>Structure:</i> 22 units, of which 15 offer home care service.	<i>Aim:</i> "Impact" study	52% were men (age > 60 yrs) 50% beneficiaries are cancer patients
		<i>Design:</i> 50 patients randomly selected from 15 palliative care units.	Major findings: Significant difference in types of physical problems faced by the patients (Chi-square = 345.495 $p = 0.01$).
		<i>Study design:</i> Retrospective descriptive survey	Pain most common
		<i>Measures:</i> Primary data for descriptive survey with structured questionnaires from the respondents.	Also ranked highly: social problems; not able to stay in job; financial problems/ medical bills
		The study period: 6 months, from July 2009 to January 2010	Major benefit of palliative care sig reduction of pain scores.

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

Dongre <i>et al.</i> , 2012, <i>India</i> . Help Age India, rural Tamil Nadu [39].	Structure:	Aim:	At palliative care programme entry physical quality of life in intervention area = 10.47 ± 1.80 SD compared to control 10.17 ± 1.82 SD ($p = 0.013$); for psychological support 10.13 ± 2.25 SD vs 9.8 ± 2.29 SD ($p = 0.043$). Programme shows no effect on domain of social relationship and environment.	Affordable and effective rural palliative care for elderly population at the village level can be set up effectively through and community participation.
	Community managed palliative care programme in villages of rural Tamil Nadu state-	To evaluate rural palliative care for older people in terms of quality of life		
	Provision:	Study Design: Prospective cohort with control comparison group.		
	Home visits by doctor, volunteer, nurse and physiotherapist. Support from Palliative care programme: Home care, Support to buy drugs, rehabilitation support, food, health education, and referral services.	Sampling: Project area (n = 450) Control area (n = 450) N = 50 elderly persons, age >60 years in 46 villages Control = 47 neighbouring villages. Measure: WHO-Quality of Life-brief questionnaire. Follow up period of study: From year 2007–2008.		
Thayyil & Cherumanalil, 2012, <i>India</i> . Local self-government (Panchayats) led community-based home palliative care [37].	Structure:	Aim:	Diagnoses/needs: 41% degenerative disease, 15.3% malignancies, 13.5% geriatric without any specific diagnosis.	The evaluation concludes that the service could address most of the medical, psychosocial, and supportive needs of the patients and reduce their
	Nurse, health volunteer, social health activist, community member, health department field worker conduct home visits.	To assess patients' status and services provided	Motor dysfunction (41.3%) tiredness (31.7%) and pain (27%), urinary symptoms (25%), bedridden (25%), ulcer (12.5%), oedema (10.6%), tube feeding (5.8%), urinary incontinence (16.3%), bowel control (9.6%)	pain and symptoms. No change data reported.

Table 2 Findings: evidence of palliative care models, interventions or outcomes from south Asia (Continued)

<i>Provision:</i>	<i>Study design:</i>	Social needs were high with 66.3% receiving cash or material support
Medical supportive care, ulcer care, catheter services and supply of accessories	Retrospective record review 2010-2011	Mean duration of care 7.8 ± 5.7 months.
	n = 104.	36.5% died during period of study.
	<i>Measures:</i> Data on patient problems and time under care extracted.	

We have noted that the majority of data have been published from India, and this suggests that they are in the relatively better position to drive forward the research activities in the region. Within India we also recognize disparity, as the papers suggest that most published work has originated in the south, mostly in or around the state of Kerala, where the literacy rate ranks among the highest in the country, and the population growth rate the lowest [43]. The fact that the search found no articles originating from Afghanistan, Sri Lanka, Bhutan, Maldives, or Bangladesh underlines the importance of undertaking work in these countries, where evidence suggests particularly poor access to palliative care and to opioid pain relief [44,45]. Qualitative studies are also needed to better understand the cultural context of death and dying for patients and their families in South Asia.

Conclusions

In conclusion, the body of evidence for palliative care in South Asian Association of Regional Cooperation countries is not reflective of the size of population in need. In light of the limited resources available for health systems, evidence is even more important to guide appropriate and effective services. Without adequate assessment, the provision of appropriate, evidence-based palliative care is unlikely to occur; the need for well-designed and validated tools to measure outcomes is paramount to advancing palliative care in a region marked by dire need for it.

Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SAARC: South Asian Association of Regional Cooperation; GNI: Gross National Income; USD: United States Dollar; ICAR: International Agency for Research on Cancer; UNAIDS: Joint United Nations Programme on HIV/AIDS; HIV: Human Immunodeficiency Virus; AIDS: Acquired Immunodeficiency Syndrome; WHO: World Health Organization; PPCS: Pain and Palliative Care Society; PCPBT: Palliative Care Patient's Benefit Trust; WPCC: Wayanad Palliative Care Consortium; NNPC: Neighborhood Network in Palliative Care; INCTR: International Network for Cancer Treatment and Research; GPPCS: Guwahati Pain and Palliative Care Society; IPM: Institute of Palliative Medicine; NRHM: National Rural Health Mission; QOL: Quality of Life; VAS: Visual Analogue Scale; PPC: Pain and Palliative Care units; NGOs: Non-Governmental Organizations.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

Both authors critically reviewed the manuscript, read and approved the final manuscript.

Acknowledgements

Dr Taranjit Singh would like to acknowledge the postgraduate education programme at the Cicely Saunders Institute, Kings College London. We would also like to acknowledge the contribution of Charlotte Wood for manuscript management.

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Received: 9 January 2015 Accepted: 31 March 2015

Published online: 30 April 2015

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